

2018 Annual Report - ILAE-Latin America

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Roberto Caraballo (Argentina)

YES- Young Epileptologists

Johann Sebastián Ortiz de la Rosa (Colombia)
Viktor Navarrete-Modesto (Mexico)

Strategic Plan for Latin America

The Strategic Plan for the region was sent to all chapters of the ILAE LA.

Academia Latinoamericana de Epilepsia (ALADE)

Annual Fellowships

The call for Annual Fellowships of the ALADE was made for all Chapters of the ILAE LA through the ILAE's website.

Overall, 28 candidates from 11 different countries applied for the fellowships.

The candidates were evaluated based on a set of preestablished criteria (CV, country of origin, commitment to return to their home country after finishing the fellowship, etc.)

The following three candidates obtained the highest scores and were selected for the training, receiving financial support:

Dr Sofía Dubon (Honduras)

Dr Anilú Daza (Colombia - Venezuela)

Dr Álvaro Sacalxot (Guatemala)

They chose the following centers for their training: 1) UNICAMP, Campinas, Brazil, 2) Hospital Ramos Mejía, Buenos Aires, Argentina, and 3) Clínica Las Condes, Santiago, Chile.

The training centers have been informed. Contact between the centers and the fellows has been established to agree on dates of initiation, etc. Donna Cunard has also been informed.

As in the past, contact with ex-fellows was sometimes lost, so a systematic form was designed in order to maintain follow-up contact with the fellows.

Itinerant Courses ("in-situ")

ALADE organizes itinerant courses in different locations throughout Latin America. Additionally, pre-convention courses are also held.

This year, the first ALADE itinerant "in-situ" course took place on June within the framework of Epilepsy Week in Tarija, Bolivia. Teachers were Roberto Caraballo, Patricia Braga, Mario Camargo, Tomás Mesa, Carlos Acevedo, and Franz Chaves. The topic of the course was entitled, 'Epilepsy in Primary Care'

The second "in-situ" course took place in Tucumán, Argentina, on August 31 and September 1. The topic was, refractory epilepsy in children and adults, etiology, and alternative and surgical treatments. The coordinators of the course were Sebastián Fortini and Pedro Nofal. The international speakers were Mario Camargo and Alejandro Scaramelli, while the local speakers were Drs Marcelo Bartuluchi, Oscar Martínez, Alberto Espeche, Santiago Flesler, Gabriela Reyes, and Roberto Caraballo,

The third "in-situ" course took place in Asunción, Paraguay, on November 2. The topic was, Epilepsy in Primary Care, and the teachers were Alicia Bogacz and Roberto Caraballo.

This year, the pre-convention ALADE course was held during the X Latin-American Congress of Epilepsy in Costa Rica on September 29, with a full-day program consisting of the following topics:

The first topic of the day was the new classification of seizures and the epilepsies, coordinated by Elza Marcia Yacubian (Brazil) with presentations by Alicia Bogacz (Uruguay), Elza Marcia Yacubian (Brazil), Lilia Morales-Chacón (Cuba), and Patricia Braga (Uruguay).

The second morning topic was Semiology and a discussion of video cases, coordinated by Alejandro Scaramelli (Uruguay) with presentations by Silvia Kochen (Argentina), Patricio Abad (Ecuador), André Palmiini (Brazil), and Alejandro Scaramelli (Uruguay).

In the afternoon, the first topic was Practical Encephalography, coordinated by Loreto Ríos (Chile) with presentations by Guilca Contreras (Venezuela), Luis Carlos Mayor (Colombia), and Loreto Ríos (Chile).

The course concluded in the afternoon, with the topic of the rational use of new AEDs, coordinated by Jaime Carrizosa (Colombia), with presentations by Jaime Carrizosa (Colombia), Emilio Perucca (Italy), and Alfredo Thomson (Argentina).

XII Latin American Summer School on Epilepsy – LASSE XII

The 12th Latin American Summer School on Epilepsy (LASSE XII) took place in São Paulo from February 15-23, 2018. From 192 applications, 64 participants (62 from Latin American countries and 2 from Angola) participated in all the activities offered by the school.

The central topic of this LASSE edition was "EPILEPSY: The Awakening of Hyperexcitability". The school was designed in such a way that the first two days were centered on discussions related to the mechanisms underlying excitability and hyperexcitability. Prof. Rodrigo Quian Quiroga, from the UK, invited as the keynote speaker, gave the first lecture, which – due to his extraordinary knowledge and didactics – set the right "tone" for the whole school. Another novelty of the program, the case-oriented discussions, were overwhelmingly praised by all participants.

As in all editions of LASSE, students were instructed to prepare, in groups and under the guidance of tutors, research projects linked to the theme of the school to be presented on the last day. The dedication and enthusiasm in the preparation of these projects could be observed by all the teachers present. The themes chosen by the student groups were:

Group 1 - Therapeutic efficacy of cannabidiol in patients with focal refractory epilepsy: A multicenter study

Group 2 - High-mobility group box 1 (HMGB1) as a biomarker of epileptogenesis in an animal model of TBI

Group 3 - High-frequency oscillation as a biomarker for seizure recurrence

Group 4 - Does neuropsychological rehabilitation and carbamazepine treatment modify the default mode network in children with self-limited epilepsy?

Group 5 - Neuronal connectivity analysis of interictal spikes and ictal activity in an animal model of TLE

Group 6 - Detection of psychogenic non-epileptic seizures with a multimodal monitoring system

Group 7 - Analysis of the blue lens efficacy in the reduction of interictal epileptiform discharges in the daily lives of patients with juvenile myoclonic epilepsy

Group 8 - Long-term effectiveness and safety of cannabidiol treatment in an animal model of focal epilepsy

All the presentations, organized by the group under the supervision of the tutors, were very satisfactory, denoting the dedication of the "students" to the LASSE proposal. The themes chosen were in line with the topic of XII LASSE and the ensuing discussions involved the participation of all present. The comments and discussions showed a proper understanding of concepts and appropriate reasoning when designing questions and explanations on the topics listed in the projects. The (theoretical) formation of Latin-American networks for the development of projects showed how much still needs to be done with regard to the specific problems in this part of the world. The teachers present at this session enthusiastically participated in the discussions and were unanimous in the positive observation of the potential of these students.

Latin American Epilepsy Online Course for Primary Care

Two online courses were developed by Jaime Carrisoza and Patricia Braga during 2018, with a total of 34 participants. The first course had 13 attendees and the second had 21. Countries of student residence covered the whole region of Latin America (Mexico, Costa Rica, Panama, Cuba, Colombia, Venezuela, Ecuador, Peru, Uruguay and Brazil). This year, we missed students coming from other

countries such as Guatemala, El Salvador, Nicaragua, Honduras, Dominican Republic, Puerto Rico, Bolivia, Argentina, and Chile.

During the 10th Latin American Epilepsy Congress in San Jose, Costa Rica, most of the online course tutors met to evaluate the course development and propose future perspectives. Strengths of the course include highly qualified tutors, the updated learning material, good student adherence and the flexibility of the platform. Of importance is the accreditation of the course of eight modules, passing the examination for each module and approving the final exam. Disadvantages are the module agenda (maybe the course should begin with another more attractive topic than epidemiology), poor communication with tutors in forums, nearly absent interaction with other students, and lower than desired registration rates.

Course changes are being considered and developed for 2019. All tutors and students rated the course as an excellent, competent, and inexpensive strategy that needs wider publicity. Details of the course regarding planning, development, and publication can be found Open Access in *Epileptic Disorders*. Further online courses will be planned during next year to begin in 2020.

Pediatric Epilepsy Training (PET Spanish Version)

Pediatric Epilepsy Training 1 (PET 1) documents and flyers from the British Child Neurology Association (BCNA) were translated from English into Spanish with the commitment of ten child neurologists coming from different Latin American countries. A reverse translation from Spanish to English should be done in 2019. Depending on the funding, it is possible that the first 'train the trainer' course of PET 1 will be launched in Bogotá, Colombia next year. Philippa Rodie, representative of the BCNA, in association with ILAE, has presented funding proposals to OPEC and the pharmaceutical industry. Some Latin American chapters are negotiating with local pharmaceutical companies and other NGOs as possible resources for this initiative.

Task Force on Epilepsy in Primary Health Care of the ILAE-Latin America Region

Book Presentation

The book, "Epilepsias en el primer nivel de atención de salud" on epilepsies in first level health care by Lilia María Morales Chacón of Cuba and Sara Silvia Kochen of Argentina has been published this year. The book was presented to the Chapters at the X Latin-American Epilepsy Congress in Costa Rica; all representatives of the chapters present at the General Chapter Meeting received a copy.

Courses of the Task Force for Epilepsy in Primary Care

On June 5-8, 2018, the course of the Task Force for Epilepsy in Primary Care entitled, "Epilepsias in Primary Health Care," was held in Cuba. The modality was a workshop/course. Physicians from all provinces of the country, as well as foreign physicians who were doing stages in Cuba, participated.

An instructional video of the course was recorded.

On December 4, the course of the Task Force for Epilepsy in Primary Care entitled, "Epilepsias in Primary Health Care," was also held in Buenos Aires, Argentina. The teachers of this edition of the course were Silvia Kochen, Lilia Morales Chacón, and Roberto Caraballo.

Paper Publication

The paper, "Epilepsy for Primary Health Care: A Cost-effective Latin American E-learning Initiative," a report from the Education Commission of the International League Against Epilepsy by Jaime Carrizosa, Patricia Braga, and Marly Albuquerque was published in *Epileptic Disorders (Epileptic Disorders, 20(5), 386-395, 2018)*.

Basic and Clinical Research in Epilepsy

Study on Genetics in Epileptic Encephalopathies

In the study on genetics in epileptic encephalopathies in Latin-America, coordinated by Dr Íscia Lopes-Cendes from Brazil, data is being collected from centers throughout Latin America.

Processing of the material has started.

Study on Cannabis in Epileptic Encephalopathies

In Argentina, a two-year trial has been started for the use of cannabis in epileptic encephalopathies. Public hospitals throughout the country are participating in the study.

The study will be a model for the use of cannabis in other countries in Latin America.

Translation of Seminal Articles

The following key articles were translated into Spanish and Portuguese under the supervision of the ALADE:

- ILAE official report: A practical clinical definition of epilepsy: Definición clínica práctica de la epilepsia, Fisher et al., 2014.
- Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology: Clasificación operacional de los tipos de crisis por la Liga Internacional contra la Epilepsia: Documento - Posición de la Comisión para Clasificación y Terminología de la ILAE, Fisher et al., 2017.
- Classification ILAE Classification of the Epilepsies Position Paper of the ILAE Commission for Classification and Terminology. Scheffer et al., 2017.

The versions in Spanish and Portuguese can be found in the Spanish section of the ILAE website: <https://www.ilae.org/translated-content/spanish>.

Fellowship in Epilepsy in Canada

A new fellowship was offered by Dr Jorge Burneo at the Epilepsy Program, Western University, London Health Sciences Center.

The fellowship is for a neurologist or child neurologist for the duration of one year with financial support of 50,000 Canadian dollars.

Requirements for the candidates were agreed upon with the center, and a call was made to the chapters and on the ILAE's website.

Dr Miguel Arévalo, neurologist of Ecuadorian and Argentine nationality, was selected for the fellowship position.

Epilepsy Week Bolivia

The IV Epilepsy Week in Bolivia was held this year in Tarija, from June 4-10, with a two-day course on epilepsy, a one-day theoretical-practical on EEG, and a two-day course on epilepsy in primary care, as well as a presentation for relatives of persons with epilepsy. Teachers were Silvia Abente, Carlos Acevedo, Patricia Braga, Roberto Caraballo, Laura Cristino, Franz Chaves, Laura Guilhoto, Oscar Martínez, Tomás Mesa, and Eduardo Medina. In the locations where Epilepsy Week was held in previous years - the cities of Santa Cruz, La Paz, Chuquisaca - local neurologists developed the courses.

Latin American Congress of Epilepsy in Costa Rica

The X Latin-American Congress of Epilepsy was held this year in Costa Rica from September 29 through October 2, with the participation of more than 600 attendees.

- Sam Wiebe was present as the liaison of the ILAE-LA.
- During the Congress, a regional chapter meeting and the commission meeting took place.
- In the commission meeting, the ILAE LA strategic plan was presented and the logo for ILAE LA was discussed.
- Further topics of the meeting were:
- On Education:
 - The ALADE
 - Curriculum: common competencies for epileptologists, neurologists, pediatricians, pediatric neurologists, clinicians, or psychiatrists
 - Primary care (Chair of the task force: Lily Morales Chacón)
 - Online courses
 - PET courses
 - Post-graduate courses in epilepsy, Master's degree
 - Consensus: ketogenic diet and cannabis
 - The task force on research was established. Coordinator: Fernando Cendes
 - There was an update on the research study on genetics in epileptic encephalopathies by Íscia Lopez Cendes.
 - The task force on national programs/pilot programs was established. Coordinator: Mario Camargo
 - The Argentine project on telemedicine was presented
 - Translation of seminal papers and guidelines was discussed
 - Representatives of the YES LA were assigned: Johann Sebastián Ortiz de la Rosa and Viktor Navarrete-Modesto
 - Representatives of the YES were proposed for each chapter
 - On the first day of the congress, the IBE meeting was held, addressed to the families
 - It was decided to hold the next congress in Santiago de Chile in 2020.

Telemedicine

- The Ministry of Health of Argentina issued a decree for a national health program in telemedicine
- Within this program, a model for telemedicine in epilepsy is being developed
- Part of the program was a symposium on telemedicine which was held in Tucuman, Argentina. A second symposium is planned for 2019 in Salta, Argentina
- The experience will serve as a model for future projects throughout Latin America
- Several countries in the region (Brazil, Colombia, México) are already working with telemedicine

Assessment of the Chapters

To assess the functioning of the chapters in the region and the opinion of the chapters on the functioning of the ILAE-LA and the Central ILAE, in order to be able to better respond to the needs, a questionnaire was sent to all the chapters by the end of the year.

The questions were designed in a yes/no fashion so as to make it easier for the respondents, with space for further comments for many of the questions.

The results are currently being collected.

Young Epileptologists - YES

Johann Sebastián Ortiz de la Rosa and Viktor Navarrete-Modesto have been assigned the task of involving the young epileptologists of the YES in the key activities in the region. They will facilitate the work of the YES in Spanish social media to disseminate activities of the ILAE Latin America.

The first achievements of the YES LA are the following:

- Twitter accounts were opened for the ILAE LA in Spanish and in Portuguese, and will be managed by YES members
- Different publications of the ILAE have been translated into Spanish and Portuguese, and published in Facebook
- The infographic material prepared by the YES has been translated into Spanish and Portuguese, and is awaiting a final check by senior members
- Currently, the YES-LA is the section that has the most members, and is the first to organize YES sections in all the chapters of the region
- Three meetings for patients and caregivers took place in Colombia to increase awareness of epilepsy, added to the activities organized by Susana Lara Meier in Costa Rica that are part of the IBE, showing the important participation of the IBE in the YES LA.
- Diego Jiménez, the YES representative of Ecuador, has, together with the local chapter, planned a course to be held in different cities of the country on continuous education and the launch of the YES. This course may be a model to be used by the YES in the region.

Joint Activities with Local Organizations, IBE, and PAHO

On February 28 and March 1 in Trinidad Tobago, a meeting of PAHO, ILAE, IBE, and the Epilepsy Society of the Caribbean (ESC) was held to improve the epilepsy situation in the Caribbean (Improving the Management of Epilepsy and its Comorbidities in the Caribbean. Regional Workshop, Trinidad and Tobago, 28 February – 1 March 2018) with the participation of Marco Tulio Medina and Roberto Caraballo. The aim of the meeting was to identify challenges and opportunities to improve access to services for people with epilepsy in the Caribbean, and to provide countries with tools, evidence, and guidance on best practices to address epilepsy at a primary care level.

A joint strategic plan has been developed for PAHO, ILAE LA and IBE LA. This strategic plan has been submitted for publication in *Epilepsy Research*.

Roberto Carabalo
Chair, ILAE-Latin America